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ABSTRACT

This paper presents a review of the literature on stress and coping in families with children having spina bifida and offers a transactional model to study the parent child interaction in these families. The conclusions drawn from the literature review are the following: both parent and child in the family setting need to be considered as both face unique specific stresses; there has been little research dealing specifically with this population; current family stress research and research on parent and sibling reactions to the spina bifida child indicates that parents often experience tension, isolation, fatigue, depression, and financial problems and siblings are often characterized by excessive investment in the handicapped child; and the child's mode of ambulation and intellectual development may be important sources of family stress. Studies of adolescents with spina bifida have indicated common social isolation, low self esteem, and feelings that their parents do not understand the disability. The transactional model offered focuses on the relationships between the child's coping strategies, the stress which these strategies generate for family members, the subsequent coping strategies of parents and siblings, and the resulting chain reaction. (27 references) (DB)

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A transactional model for investigating stress and coping in spina bifida children and their families: justification and presentation

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Within the last twenty years the use of antibiotics and advances in neurosurgical techniques have reduced the death of congenitally, physically disabled young people in our community, and growing numbers are reaching adolescence and young adulthood. Little information exists about the problems of these young people, whether their problems are specific to their disabilities, or about the ways in which they cope. Nor do we have information about their parents' stressors and coping mechanisms and resources.

Related literature suggests that both parent and child in the family setting should be considered: The family coping style seems to affect the coping processes of adolescents with aplastic anemia.[1] Non-handicapped children's perceptions of the stressfulness of life events often differ from those of adults,[2] and the way family life is viewed by both parents and the children is important for the presence or absence of emotional disturbance in the child.[3]

In the spina bifida family, both the adolescent and the parent face unique specific stresses in addition to those life events common to other adolescents and their parents. Because of the nature of the handicap most spina bifidas are socially isolated within the family setting.[4] Parents of these children must cope with the usual problems of guiding a child through adolescence compounded by the unique problems which this handicap presents...problems of dependence/independence, information about the future, the ventilation of frustrations, fears, discouragement, and resentment.

Adolescents with spina bifida are in the difficult position of dealing not only with implications of their handicap but also with the typical issues that attend that developmental stage. In addition, these adolescents are prevented from using the traditional channels and peer supports to establish identity and independence.

PARENT AND SIBLING STRESS AND COPING

Little research has been reported dealing specifically with stress, coping, and spina bifida families. Some insight can be gained from more general articles on spina bifida children, their siblings and parents, and from research dealing with the chronically ill or severely disabled children and their families. Eisen[5] notes that the effects on families through their containing a chronically ill child are insufficiently recognized. He points out that there are direct stressor effects of chronic physical illness in childhood that are difficult to evaluate because of lack of research on particular responses of these children. There is evidence of the extreme stressor effects of the long-drawn out investigation, treatment and life support measures undertaken.

Current family stress research has attempted to measure both the family's internal resources, i.e. integration or adaptability to handle social or psychological stresses, and the range of the family coping strategies which also include the role of social support in management of family stress. They found that families with low stress were higher on family environment measures of cohesion, recreation, and organization, and lower on measures of conflict, than were the high stress families. The severity of the child's mobility was also higher in high stress families. When coping

strategies were examined it was found that low stress families scored higher on the strategy "Developing Family-Community Relationships". The instruments used in this study were Holroyd's Questionnaire on Resources and Stress and McCubbin's Coping Health Inventory for Parents.[6]

Research on parent and sibling reactions to the spina bifida child reveal some of the stressors experienced, methods used for coping, and resources desired but unavailable in times of stress. Parents experienced tension, isolation, fatigue, depression, interference with domestic routines, and financial problems. Neighbors provided little support or assistance but evidenced curiosity. Siblings in the same study reacted to the parents' reactions. Excessive investment in the handicapped child was common among these siblings.[7]

However, the result of this concern can be very different. Meijer[8] studied a population of families with spina bifida children in Israel, and found that many mothers demonstrated a deep emotional involvement often causing mental pain, leading the mother to assume a self-protective attitude, retreating emotionally or even physically from the child.

Parents in the study by Hare et al.[9] mentioned emotional strain and anxiety, and physical and psychological stress. The author noted that many other factors could escalate this stress level: parent ill health, needs of other children, father's unemployment, unsatisfactory housing conditions, living with in-laws, etc. These parents found relatives and neighbors sympathetic and helpful and didn't mind them knowing about the child's condition. However, they did feel that they could have had more help and advice from health professionals who didn't emphathize or understand their anxieties.

An aspect of the spina bifida child's disability which has received some attention is mode of ambulation, and opinions about the stress which this generates vary. Carroll[10] feels that the relationship of the child with society in general is grossly affected according to the child's mode of ambulation. Eisen[5] does not view this with the same degree of importance. He found that the vulnerability to stressor effects of chronic physical illness is related to age, family relationships, and social factors more than to the severity of the physical disability. Kolin[11], points out that the severity of the physical impairment is not the primary determinant in the level of adaptation attained by the child with meningoymyelocele, that social and emotional factors and parental adaptation influence the child's eary adjustment. He also emphasizes the importance of the physician's emotional support and guidance for the parents. However, Holroyd[12], studying stress in families of children with neuromuscular disease, reported that parents whose children were in wheelchairs scored significantly higher than those whose children were ambulatory on six scales on her questionnaire: Excess Time Demands, Overcommitment/Martyrdom, Limits on Family Opportunity, Physical Incapacitation for Index Case, Lack of Activities for Index Case, and Occupation Limitations.

The intellectual development of spina bifida children may be stressful for family members. In general there appears to be a discrepancy of about 15 points between the performance of the spina bifida child and siblings evaluated with the same instrument. Adjustment among siblings with higher intelligence may be difficult particularly at ages when siblings are not mature enough to understand the deficiencies of the handicapped child.[13, 14, 15, 16, 17].

SPINA BIFIDA CHILD'S STRESS AND COPING

McAndrew's study of thirty-five adolescent spina bifidas reveals the following problems and stressful situations. Functional impairment became a problem only if it caused frustration in activities of daily living or embarrassment. Half the group were socially isolated, only two had steady relationships and went out regularly. Nevertheless only one or two said that they had no close friends. Two-thirds were never bored or lonely, but were frequently depressed. They found the disability hard to accept and to cope with and were uncomfortable, embarrassed and disheartened. They anticipated difficulties in walking, finding a marriage partner, finding suitable employment and making and keeping friends. It has been pointed out that teenagers who have strong dependency needs on their families are in a less advantageous position to attract and maintain close friendships.[4] King[18] has stated that the social isolation and difficulty in forming friendships can be explained in terms of the negative, unproductive personality characteristics of the disabled which lead to rejection by peers. This, in turn, may be related to low self-esteem; since disability commonly undermines self-esteem.[19,20,21] Two-thirds of McAndrew's subjects reported low self-esteem.[4] Wright[22] suggests that to foster self-esteem it is important to focus on the individual's coping aspects.

Parents of McAndrew's adolescents spina bifidas were characterized by their children as lacking in understanding and empathy. The children felt that the parents didn't understand the disability, how it affected their moods and decisions and their need for independence.[4] It would be difficult

for a parent to understand since the adolescent problems and the intensity which they were felt did not remain static but changed over the years.

The Declaration of the rights of the Child adopted by the U.N. in 1959 included the right to love and understanding, the handicapped child's right to special care, and the child's right to become a useful member of society[23]. Also, the importance of the relationship between stressful life events and psychopathology has been established.[24] Eisen[25] has pointed out that many of the rights of children are based on the child's need for protection from undue stress, and that there still remains the argument about the plasticity of children's response to stress. Most research is based on stressors designated by researchers and we do not know whether or not children perceive the research designated stressors as actually producing stress. Nor do we know whether families' established stress-coping strategies contribute to the development of their children's stress-coping techniques.[26]

A RESEARCH MODEL

A transactional model has been developed from work with infants and their caretakers.[27] This could provide a basic approach to the study of the parent-child interaction in stress and coping in the spina bifida family. This model begins with a mother stressed emotionally, socially and economically, who produces a child to whom these stresses are communicated producing in that child a difficult temperament. The negative characteristics of the child provide little reinfrocement for his parents and consequently, unless they are free of other social stresses, they, in turn, do little for the child. This results in a reciprocal process by which the child and parents march down the road to a less than positive

developmental outcome.

A transactional model, Figure 1, is proposed for investigating the strategies which spina bifida children employ to cope with the stresses and strains consequent to their birth defect and to determine how parents and siblings cope with the event. Of specific interest are the relationships between the child's coping strategies, the stress which these strategies generate for family members, and the subsequent coping strategies of these parents and siblings. The continuing chain reaction wherein the child must then cope with the further stress generated by his family's coping is the second dimension.

Children's behavior triggers off parental reactions and vice versa. Ways in which the spina bifida child copes with the disability could produce stress for parents and siblings who, in coping with this stress, generate further stress for the disabled child. The chain reaction also operates from the starting point of parent and sibling coping.

(insert Figure 1 here)

Investigation of stressors and methods of coping of the spina bifida child, the parents and the siblings, and analysis of their responses could reveal relationships and chain reactions which create further stress. Such information would be valuable in counseling and assisting the family to more effectively manage the child's care. More specifically, should parents answer a questionnaire or participate in an interview situation focusing on the specific aspects of the child's problem or behavior which cause stress, and thus examine their own coping mechanisms, then, these parents should receive, in a concrete manner, insight into their own reactions and behaviors.

Understanding the way in which their coping produces additional stress for the child, should lead to discussion of possible alternative reactions which could result in less stress for the child and which might eliminate the need for further unnecessary coping on his (her) part. In addition, awareness of the pattern of coping responses to stress could enable the parent or the child to develop some less distressful system of stress management. A more cooperative effort to lighten the stress of coping with the condition for the spina bifida child, the siblings and the parents could evolve from the information gathered on the family and the feedback and counseling which could follow.

Also, information on behaviors which are common to most same-aged children could serve to place the spina bifida child's behavior in a more favorable and acceptable light. If all parents experience similar situations with normal children in the family setting, then the spina bifida parents may see the behavior as less stressful.

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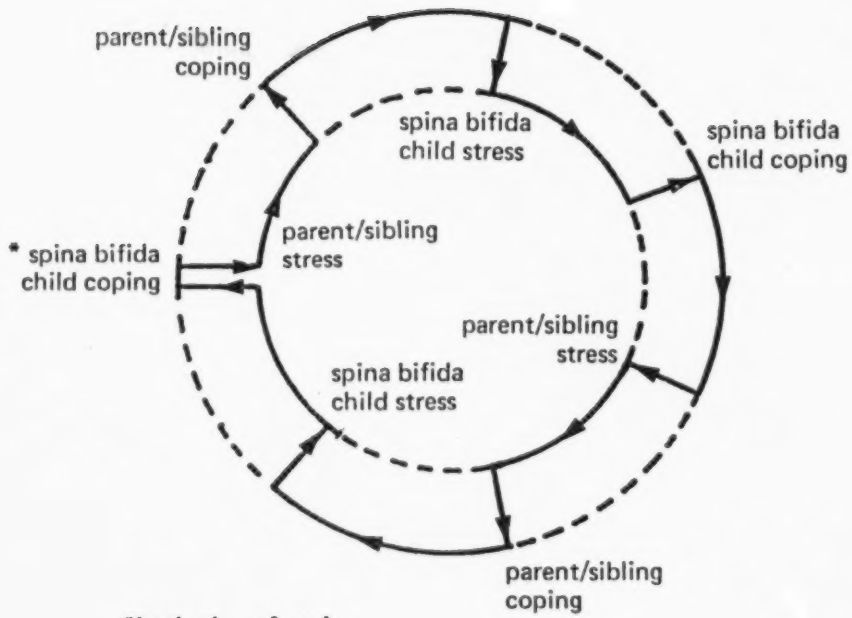

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